Advance Directives
The Missing Conversation
Why Our Patients' Children Are Left Holding The Bag

SC Chapter
American College of Physicians
October 29, 2014
Sewell I. Kahn, MD FACP

End of Life Planning
Barriers
- Lack of healthcare time and training
- Politics
  - Death panels
  - Terri Schiavo
- Aversion to talking about death
  - Physicians
    - 85% Medical Residents uncomfortable talking about death
  - Patients

Patient's Beliefs
- Some cultural or religious beliefs
- Some distrust of medical system
- Their spouse or children know what they want
- Their children agree on a single approach
- The doctor will make the decision
- Will be able to make decisions when the decisions will be needed
End of Life Planning Facts

- Planning too late
  - 40-96% lack capacity to make decisions
  - Illness, stress, medications may hamper thinking processes
  - Unexpected illness and accidents
- Low rates of advance directive completion
  - 15-30%
  - No discussion
  - Not available

Lack of Planning Impact

- Inappropriate care
  - Too much
  - Too little
- Waste of time and resources
- Dying in hospital or nursing home rather than at home
- Moral distress
- Impact on surrogates

Impact on Surrogates

- 1/3 have a negative emotional burden:
  "I will never get over letting mother die"
- The emotional burden is much less negative if patient’s wishes are known:
  "Thank God Mom and dad had a living will. I am glad I was not the person making the decision"
Planning Ahead

Problems

- Hard to predict what the situation will be when decisions are needed
- Each situation has many variables
- People's values and desires will change over time
- Understanding the medical facts will be difficult at the time of decision making
- Situations often do not fit standard Living wills

The 2 Conversations

- Advance Directives
  - Patient
  - In relatively good health
  - Near EOL
  - Patient or Surrogate
  - Critically Ill

Life Planning

- Think about values and discuss with family and others
- Update decisions and documents as medical situations change
- Update plan with health care providers
- Fill out Advance Directive and discuss general values with surrogate and HCP
- Revisit decisions and documents as patient and situation change
- Revise plans with specifics related to illness
- POLST type document
- EOL Discussions: Patient or surrogate and health care providers for specific actions

Early Visits

Annual Visits

Onset of Chronic Illness

Onset of Serious Illness (≤1 year survival)

At EOL
Values

- Introduction:
  
  You are in good health and are doing well, however I like to have a discussion with all of my patients young and old about life planning in case of serious illness or accidents.

- Resource:
  
  http://theconversationproject.org

Advance Directives

- Introduction: In SC we have 2 + legal documents:
  
  - Living Will
  - HC Power of Attorney
  - 5 Wishes

Advance Directives

- Resources:
  
  - http://aging.sc.gov/legal/Pages/AdvanceDirectives.aspx
  - http://www.agingwithdignity.org/forms/5wishes.pdf
Advance Directives: Living Will
South Carolina

- Specific situations
  - Permanently unconscious
  - Terminally ill
- Specific patient’s instructions
  - Life sustaining treatment
  - Artificial feeding and hydration
- Provision to designate a person to:
  - Enforce
  - Revoke

Advance Directives: Healthcare Power of Attorney
South Carolina

- Has the power to make all healthcare decisions for a patient if the patient does not have the capacity to make decisions
  - All treatment and diagnostic procedures
  - Life sustaining treatment
  - Hydration and nutrition
  - Admission and discharge decisions
  - Other

Advance Directives General Comments (1)

- The advance directive is only valid if the patient does not have capacity to make decisions
- The advance directive should be available when needed.

Copies:
- Personal medical record
- Surrogate
- Lawyer
- Personal physician
- Rabbi or minister
- Accompany patient to healthcare facility
Advance Directives
General Comments (2)

- It is *NOT* the HC power of attorney document that
speaks, but the *person* who is appointed, therefore
discussion of needs, values and desires with that person
is needed.

- A patient may change or revoke all advance directives.

- If there is both a HC power of attorney and a Living Will,
The surrogate *CANNOT* change the Living Will unless
the patient has given power to revoke.

 Advance Directives
General Comments (3)

- SC Law: If a patient does not specify in the
Living Will that they do not want food/water they *WILL* receive it.

- Advance directives are not perfect

- Advance directives are *not* doctors’ orders

- Only apply when in a healthcare facility

- Not portable

Revisit or document review

- Introduction:
  - Have you completed an advance directive at another elsewhere?
  - Or
  - I know you filled out an advance directive in the past. Has your
  situation changed?
Advance Care Planning
Physician Involvement

- Only 12% of people with advance directives have input from their physician
- 65% - 76% of physicians are unaware the patient has an advance directive

The Agency for Healthcare Research and Quality’s (AHRQ)

Onset of Chronic Illness

- Introduction:
  With the diagnosis of chronic illness, life-threatening or life-changing illness specific issues may need to be discussed

Resources:
Prepare:
www.prepareforyourcare.org
This is an interactive website that guides patients in discussions with family and decision-making
Serious Illness

Introduction:

We know that this illness is going to limit long term survival and need to make some hard decisions.

POLST type document

Only for these patients:

- Terminal illness
- Advanced disease:
  - A health care professional would not be surprised if patient died within one year.
  - Debilitating chronic progressive illness

Documents:

- SC EMS Do Not Resuscitate form
  - Only for patients in poor health and unlikely to benefit from resuscitation
  - Only a physician can obtain form
- POST (physician orders for scope of treatment) (In development)
Developing Programs
National POLST Paradigm Programs
Endorsed Programs
Developing Programs
No Program (Contacts)

As of March 2013

POST(1)
South Carolina
- CPR
- Feeding and Nutrition
- General Medical Care
  - Intensive Care
  - Intubation and Airway management
  - Cardioversion
  - Medical Treatment
  - IVs

POST(2)
South Carolina
- Level of Care
  - Full
  - Limited
  - Comfort Measures
- Patient or Surrogate
- Doctor’s Order
- Portable
Palliative Care

- Palliative care is comprehensive, interdisciplinary care designed to promote quality of life by meeting the physical, social and spiritual needs of patients living with a serious or incurable illness.

Hanson; NC Med J 2004;65:202

Hospice

- Hospice is a system of care that provides palliative care and emotional support for patients who are in an end of life situation usually in a home or non-hospital setting. There are inpatient Hospice Care programs for patients who do not have adequate in home support.

Conceptual Shift from “Curative Model”

- Life Prolonging Care
- Hospice Care
- Palliative Care
- Medicare Hospice Benefit

Old

New
End of Life

- Options:
  - Active care with palliative care
  - AND (allow natural death)
  - Hospice

EOL Discussions: Patient or surrogate and healthcare providers for specific actions

Introduction:
- Honest discussion about options
- Prognosis
- Speaking with one voice

No Advance Directive

SC Law (1)
1. Court Appointed Guardian
2. Attorney in fact
3. A person given priority to make health care decisions by another statutory provision
4. Spouse
5. Parent or adult child
No Advance Directive
SC Law (2)

6. Adult Sibling, Grandparent or adult Grandchild
7. Any other relative by blood or marriage that the Health Care provider believes has a close personal relationship to the patient.
8. A person given authority to make health care decisions by another statutory provision.

In situations of emergency or if there is no one to consent in certain situations the patient will be treated.

Surrogates
Qualifications

- Willing
- Needs to know patient’s preferences and values
- Honor and follow plan
- Ability to make difficult choices
- Available

Surrogates

How surrogate decisions should be made:
- Patient’s wishes
- Substitute Judgment
- Best Interest
Life Planning

- Think about values and discuss with family and others.
- Recall decisions and document at each visit.
- Revisit plans and values as health changes.
- POLST type document.
- Document discussion with surrogate and HCP.
- Revisit decisions and discuss.
- Revise plans with specifics related to illness.
- EOL Discussions: Patient or surrogate and healthcare providers for specific actions.

Early Visits
Annual Visits
Onset of Chronic Illness
Onset of Serious Illness (≤1 year survival)
At EOL

Toolbox
- http://theconversationproject.org
- http://aging.sc.gov/legal/Pages/AdvanceDirectives.aspx
- http://www.agingwithdignity.org/forms/5wishes.pdf
- www.prepareforyourcare.org